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ABSTRACT

This paper discusses the symptoms, causes, and diagnosis of fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE). It then presents information from biological and adopted parents of 14 individuals (ages 4-23 years) diagnosed with FAS or FAE, based on a parent survey concerning behavioral and educational histories of their children. Behavior patterns were characterized by impulsivity, hyperactivity, poor attention span, poor judgment, and difficulty in remaining on task. Use of a structured environment was found to be necessary to control and change behavior; this structure involved a systematic schedule followed very consistently and a set pattern of consequences for problems. Common areas of behavior problems were dealing with consequences, learning from their mistakes, and having the ability to generalize consequential information to other circumstances. Unusual, erratic sleeping patterns were commonly reported. Behaviors such as lying, stealing, and inappropriate sexual behaviors were occurring, regardless of the secure stable environment provided by parents/caregivers. School issues included their need for individual attention, their need for reteaching, their resistance to rules, their hypersensitivity to criticism, and other problems. Characteristics of the "most successful teachers" and the "best year in school" are outlined and contrasted with characteristics of "least successful teachers" and "least successful school years." The survey instrument is appended. (15 references) (JDD)

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BEHAVIORAL ASPECTS OF FETAL ALCOHOL SYNDROME

by Karen Stuut Rice

For centuries, women in various cultures have been warned to avoid the consumption of alcoholic beverages during pregnancy due to the problems alcohol causes for a developing fetus. Today these problems are known as fetal alcohol syndrome (FAS), a widely recognized pattern of birth defects characterized by growth deficiency, central nervous system disorders that may include mental retardation, and major and minor physical malformations that may include a very specific pattern of facial features.

Since the first case reports on the effects of alcohol on pregnancy were published in France (Lemoine, Harousseau, Borteyru, and Menuet, 1968) and the United States (Jones and Smith, 1973: Jones et al., 1973), over 3,000 papers have been published on this subject. Both FAS and the lesser damage called FAE, fetal alcohol effects, are now accepted as major public health problems in the United States. In fact, prenatal alcohol exposure is now accepted as one of the leading causes of mental retardation in the Western world (Abel and Sokol, 1986).

FAS is characterized by a cluster of congenital birth defects caused by heavy consumption of alcohol during pregnancy that include the following: prenatal and postnatal growth deficiencies; a particular pattern of facial malformations, including a small head circumference, flattened midface, sunken nasal bridge and a flattened and elongated philtrum (the groove between the nose and upper lip); central nervous system dysfunction; and varying degrees of major organ malformations. A diagnosis of fetal alcohol effects (FAE) may be given to a child who does not meet all the criteria of an FAS diagnosis, but experiences learning disabilities and behavioral problems with a history of maternal consumption of alcohol in pregnancy. FAE is also used to describe the effects of 1-2 drinks per day to decreased birth weight, growth abnormalities and behavioral problems (Little and Ervin, 1984). The incidence of FAS is currently estimated at 1 to 3 per 1,000 live births, according to the National Institute on Alcoholism and Alcohol Abuse (Warren, 1985). March of Dimes publications list an incidence rate of 1 per 750 live births. Incidence rates of FAE range of 3 to 10 times the incidence rate of the full-blown syndrome.

With the increasing awareness of the risks of prenatal alcohol exposure, the numbers of individuals diagnosed with FAS and FAE are also increasing. A clinical diagnosis, FAS/FAE are usually diagnosed by a geneticist, dysmorphologist, behavioral or general pediatrician. Consistent diagnosis of

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FAS/FAE is more readily available now throughout the United States, and each diagnosis is bringing increasing questions from growing numbers of educational and social service professionals regarding appropriate educational and social models for these individuals.

Though our knowledge of FAS/FAE continues to increase with additional research, this author is not aware of any handbook for caregivers and professionals regarding the wide spectrum of life-long behavioral, educational and social difficulties experienced by individuals with a diagnosis of FAS or FAE. Because diagnosis is not yet wide-spread and research efforts have concentrated on the medical and physiological aspects of the syndrome, biological parents, adopted parents, foster parents and guardians of individuals with FAS/FAE often find themselves in the frustrating situation of educating medical, educational and social service professionals regarding the wide spectrum of FAS/FAE behaviors and individual needs of the child or teen in their family.

These parents/caregivers, are often overlooked by professionals as a valid source of information and expertise regarding the problems and needs of their children. Living each day, every day, with their child makes them excellent sources of information for professionals dealing with clients and patients with FAS/FAE. These parents/caregivers have years of specific experience in dealing with the behavioral, educational and social difficulties of their children. For many caregivers dealing with the day-to-day, often minute-to-minute difficulties of behavior has become an ongoing lesson in structure, consistency and patience.

This article is a compilation of information from 15 biological and adopted parents of 14 individuals diagnosed with fetal alcohol syndrome or fetal alcohol effects. These parents participated by answering a 44-question survey concerning the behavioral and educational histories of their children (see appendix). These surveys were sent to 22 families known to the author with a child diagnosed with FAS or FAE. Fifteen of the surveys were returned.

The individuals with FAS/FAE in this survey range in age from 4 years 5 months to 23 years old; two of the individuals with FAS/FAE are currently in residential treatment and training facilities, the others are residing with their biological or adoptive parents. The IQ range for the individuals is consistent with the research: for those with an FAS diagnosis the IQ range is 60 to 94; for those with an FAE diagnosis IQ scores are 106 to 112 (No IQ was available on the youngest FAE participant) (Streissguth, 1986). The respondents of this survey reside in the states of Illinois, Iowa, Kansas, Minnesota and Nebraska.

The responses of the parents/caregivers to this survey will serve simply as an example to educational and social service professionals regarding the very broad spectrum of behavioral difficulties that correspond with FAS/FAE diagnoses. It is hoped this article will offer all professionals working with this population an "inside" view of life with individuals prenatally-exposed to the effects of alcohol during pregnancy. This information also offers to the reader an increased understanding of the diagnosis, as well as the trials and successes experienced within these families. The information presented here has the potential for offering other caregivers and professionals a source of ideas and successful methods that can be tried and modified for use with others with a diagnosis of FAS/FAE.

Description of Behavior Patterns

When asked to describe the behavioral patterns of their children, our respondents provided information similar to that described by Streissguth (1986) as the behavioral phenotype for these children. "Behavioral characteristics that we have observed with increasing frequency from our extensive clinical experience with children with varying manifestations of FAS," Streissguth (1986) reports, "include impulsivity, hyperactivity, poor attention span, lack of inhibition, overfriendliness, overinquisitiveness, poor social judgment, poor

sensitivity to social cues, excessive demands for physical contact and affection..." Streissguth goes on to list as common characteristics a lack of stranger anxiety, difficulty in remaining on task, disrupted sleep patterns, and an unresponsiveness to verbal caution.

Following is a collection of descriptions from our participants regarding their children's behavior.

> "My 12-year-old is easily frustrated, becomes angry and acts without thinking through the consequences. He acts without thinking in social situations where no one is available to cue him, so he appears rude to people who do not know him. He often lies."
>
> The four-year-old was described: "tends to be impulsive and wants his own way. At home and around his family he tends to throw tantrums when he doesn't get his way. He was also slow developing physically in some ways."
>
> A nine-year-old adopted daughter is described as: "needs help completing assigned lessons and tasks. Sometimes has temper tantrums. She requires more patience and understanding; she needs more encouragement and support."
>
> A seventeen-year-old son who was adopted at 3 years of age "was a very angry child. He does not bond with anyone but is somewhat better now, though it is still difficult for him to show love. It is hard to reason with him and hard for him to stick to anything. He has a problem concentrating on anything; his attention span is still very short. He steals food and can be very destructive."
>
> A 12-year-old with FAE is described by his mother as having "difficulties with: judgement, deciding between right and wrong, rage, frustration, fitting in with his age group, acting on impulse, lies, denies his behavior and does not respond to consequences. My other children learn quickly. They do not want to repeat the consequences. But this child is still repeating things he started doing as a toddler. He never seems to learn from his mistakes."
>
> A 16-year-old with FAS is described by his mother as "hyperactive, very easily distracted. He masturbates in front of people. He hits our daughter and says sexual remarks to her. He is very compulsive and repeats actions many times. He gets locked into one subject at times and can't drop it. He is noisy, sometimes rude."
>
> A nine-year-old with FAE is described as "very hyperactive, impulsive, more immature in social relationships, blows up easily."
>
> The biological father of a 14-year-old son with FAS described him as having "impulsive behavior, inability to distinguish right from wrong. Occasional inappropriate behavior."

Eleven of the 14 individuals were described by their parents/caregivers as being hyperactive. Three of the 15 caregivers responded that their children were not considered hyperactive. Two of these three individuals have diagnoses of FAS, one of FAE.

Individual levels of fluctuation or consistency in motor behavior were reported by the 12 caregivers of hyperactive individuals. Whereas some reported no change from infancy or childhood, others commented on gradual changes.

> "As she gets older she is calmer and we try to help her get rid of her excess energy in constructive ways."
>
> "His hyperactivity seems to fluctuate, depending on the pressure on him. In infancy he thrashed limbs all waking hours. Kindergarten - he was uncontrollable. Elementary school the hyperactivity came in cycles, but in junior high, he is uncontrollable."
>
> "In early childhood he ran from one thing to another; did not concentrate on any toy. In preschool he would run around the room, pick on

other children, throw toys. Elementary school he began to calm some, wandering at night and getting into things. Junior high brought him a hard time with math, with a tendency to be a loner. When he couldn't understand his school work or homework, he would walk out of school or home."

At nine a child with FAE is described as "runs around less but he fidgets whenever he has to sit still."

One caregiver describes the hyperactivity of his 14 year-old with FAS as "consistent" from infancy to junior high.

Another parent of an FAS 16-year-old also reports "I don't know that it has changed."

Structured Environment

All respondents of this survey report that a structured environment is necessary to control and change behavior. Meals, bedtime, snacks, household "chores" are all an integral part of a consistent daily schedule, regardless of the age of the child. A structured environment within the home can be described as a systematic schedule followed very consistently that includes all activities of the day, with a set pattern of consequences for problems that can and according to many parents, do arise every day.

Giunta and Streissguth (1988) stressed the need for a structured consistent environment to maximize the potential of an FAS/FAE individual. "Patients with FAS need a supportive, loving home environment in which they can develop to their full potential. A structured family setting with clear guidelines and clear communication is optimal."

For a nine-year-old daughter with FAS, her parents share: "We have regular meals where we sit down together. She helps with the household chores, such as setting the table, unloading the dishwasher and feeding the pets. During school it is important that she gets her sleep, therefore she goes to bed almost every night at 8:30 p.m."

"Our daily routine is quite structured. We are consistent with house rules - even with sitters. We tend to intervene quickly and not let problems escalate."

A 12-year-old with FAE, "needs the same daily routine every day. A calm setting, meals on time. It's very important he knows you mean now and he gets no second chances. Rules are outlined very clearly."

"Growing up with a very strict routine, because he had trouble learning to get dressed by himself. Lunch, snacks, bed are strictly scheduled. At 17 he still responds best to routine. At 17 when 7 p.m. comes he will get up in the middle of good TV and go to bed."

For another 12-year-old structure is also important. "He has always had set times for naps, bed, baths, etc. I expect to know where he is at all times. He now comes home from school before I get home but he must call as soon as he arrives and get an okay for snacks, to go to friends, etc. He has chores he is expected to do or lose privileges. His tutor makes sure his homework is done."

The parent of a 23-year-old with FAS remembers: "I set up a highly structured home, because he seemed to do well with this. For example, he did his chores on Saturday morning. He could do his chores if we made a list together and he checked off his list as he did the tasks. When he presented his list checked off and had 'inspection' he got rewarded by allowance and got taken to town to spend it immediately. He seemed happy in a structured environment like this."

A Day in the Life of a Child with Fetal Alcohol Syndrome

The following daily schedule is used in one family with their 17-year-old son with FAS.

6:00 a.m. Get up
6:30 a.m. Help with breakfast
7:00 a.m. Breakfast
7:20 a.m. Brush teeth, get coat on, get books, etc.
7:30 a.m. Go to school
11:45 a.m. Lunch
3:15 p.m. Picked up at school.
(At 17 still can not take bus by himself without becoming disoriented.)
3:35 p.m. Home
3:45 p.m. Snack
4:00 p.m. Saxophone practice - 20 minutes
4:30 - 5:30 p.m. Homework. If no homework, outside (football, running, etc.)
5:30 p.m. Supper
6:30 p.m. Washes dishes, does own ironing.
7:00 p.m. Choice of working on models, TV, reading.
9:00 p.m. Bed

With age, rules and structure changes in every household, according to the survey, just as with any child. Most parents of adolescent and teenage individuals with FAS/FAE reported that age has brought more latitude, more flexibility in schedules, and more opportunities for decisions by the child. Two parents of older children reported little change in behavior and structure over the years.

Dealing with Consequences

Dealing with consequences, learning from their mistakes and having the ability to generalize consequential information to other circumstances is an area of difficulty mentioned by all participating caregivers. All of these children and teens are living in environments with "house rules." How they deal with these rules, and the consequences of breaking these rules is an area of frustration for all the individuals and their families who participated in this survey.

The 17-year-old with FAS has difficulties with "doing as he is told, following directions, not getting into food and other people's private things." When breaking the rules brings consequences, this individual responds by "getting very angry. He is always being treated unfair. And it is never his fault."

A 12-year-old with FAE has the most trouble with the house rules regarding brushing his teeth, bothering his mother while she's on the phone, asking the same thing over and over, and getting permission before doing a questionable activity. His response to the consequences of breaking these rules is common: "Consequences mean nothing to him. He always repeats the wrongdoing, no matter what the consequences are or how bad he hates them. It seems as if he truly forgets. When he gets in trouble for an incident and there is a consequence the next time he does the same thing he says, 'What did I do? I know I was in trouble last time, but why again?'"

Another 12-year-old with FAS has the most trouble with the house rule that restricts his getting up at

any time of the night without still waking his parent. "When a rule is made and the consequences are given he seems to understand and accept them. When a rule is broken he then wants it changed or dropped and becomes angry and argumentative."

The caregiver of a 14-year-old reports his son still has difficulties playing in a defined area without supervision. He describes the way his son responds to consequences in one word: "over reaction." He shares: "after getting in trouble with another child a year ago, he still goes wild when he sees him, even from a long distance."

A nine-year-old with FAS responds to consequences with anger. "She may yell, stomp her feet, slam doors, and cry depending upon her degree of frustration."

Even the parents of a four-year-old with FAE reports their child has difficulty leaving his brother's things alone. His parents report that his behavior seems to change with reasonable punishment, but shared this typical incident:

"Just now he got his brother's bag of candy ...because he wanted candy. He told me it was his even though he has eaten his. He has been told to leave his brother's things alone and is punished for taking them. He has been denied any sweets for today."

Another shared incident from the parents of a 17-year-old with FAS also deals with food. "He's always getting into and stealing food. We've tried everything. Just two weeks ago he did it again. He says he wasn't hungry he just wanted it. We told him with this behavior he could not get his driver's permit. He said: 'Oh well, I'll wait till I'm 18.'"

Another parent/caregiver reports this incident regarding consequences. "I once found a broken glass while cleaning and when I asked he denied doing it. Then he was guilty also of lying. When given the consequences he finally admitted he did it but several days before so he shouldn't be punished since he didn't do it today. It is always a battle to admit any wrongdoing."

But many parents also report the failure to learn consequences in relation to safety and the consequences therein. A classic description of such an incident is shared by the parent of a nine-year-old with FAE. "He would pull out the dresser drawer and climb on it causing the dresser to fall on him. He would do this same activity several times a day without ever being able to learn not to climb on the dresser."

The 23-year-old in our sample seems to have a better understanding of some consequences, but his parent still reports that he has difficulty rising on his own and does as little personal hygiene as possible, a common complaint. "Predicting and understanding consequences has always been a problem...He seems to see the consequence when he lives with someone who praises him extravagantly for doing the desired act. But when the praise and structure are gone he has trouble even getting out of or staying out of bed." On the positive side, this parent did report, however, that when he was hospitalized for alcohol problems, her son joined AA, has continued to attend meetings regularly, and has been sober for about one year. His AA sponsor is apparently his "best friend" and her son is getting the praise for his abstinence from alcohol.

Sleeping Patterns

Unusual, erratic sleeping patterns are commonly reported in FAS/FAE literature (Streissguth and LaDue, 1985). In this study sleeping disturbances are listed as another characteristic of the behavioral phenotype. All of our respondents cited a variety of difficulties dealing with sleeping patterns. Though bedtime is a consistent part of the daily schedule in these homes, sleep does not come easy for these youngsters and a lack of sleep or change in the amount of sleep was often cited as a primary cause of additional behavior problems.

For their children and teens, parents/caregivers

reported that often bedtime meant laying in bed for more an hour or two before falling asleep, sleeping fitfully for short periods of time and excessive nocturnal activity.

For one child, sleep patterns were described as erratic. "He seems to need more sleep than others his age. Goes to bed late, gets up early and may wake up in the middle of the night and be awake for several hours. As a very young child of two he was up and down all night and would wander around the house fearlessly often without turning on the lights. Now he seems to sleep for longer stretches and just watches TV."

For the 17-year-old with FAS, sleep is still difficult. "He is up and down to the bathroom; sleeping, then awake; looking at the stars or rain. He is getting better," his parents reports. "He is getting so he sleeps longer at night."

For the parents of a nine-year-old with FAS the problem is improving with age. "The same problems exist but we can explain things to her, such as the importance of rest and why she needs to stay in bed and close her eyes to go to sleep...Instead of consequences for getting out of bed, we offer rewards for staying in bed. We stay with her until she goes to sleep."

Several of our respondents reported the need for a lock on the door of the bedroom of their children with FAS/FAE when their children were very young and that nocturnal wandering was extreme.

> "As a child I would lock his room at night so if he woke up I was also awakened, so he didn't fall down the stairs or injure himself."
>
> "We initially had to lock him in his room at night - we worked on teaching him to stay in his room when it was night. It stopped, but lately we have had more difficulties."
>
> "He would get up in the middle of the night as a toddler and leave the house. He'd head outside, no clothes, no coats in the winter. By age four it had changed to 6 a.m."

Caregivers of FAS individuals ages 14, 16 and 23 all report difficulty in dealing with ongoing sleeping disturbances.

> "He doesn't sleep all night so we would let him stay up late."
>
> "He awakens in the middle of the night, returns to sleep and then is tired in the morning."
>
> "When he was a child, he could not fall asleep at night. Going to bed meant to him, go up and 'roll' for half hour, hour, etc. I'd hear him rolling in the middle of the night...He seems to have days and nights mixed up."

Inappropriate Behaviors

The subject of inappropriate behaviors has been addressed by many who research and work with the population of FAS/FAE individuals. Robin A. LaDue, Ph.D., clinical psychologist and member of the faculty of the Department of Psychiatry and Behavioral Sciences at the University of Washington at Seattle, addressed the topic "Substance Abuse, Child Protection, and the Law" at a meeting sponsored by the Law/Psychology Program at the University of Nebraska/Lincoln in August, 1991. LaDue spoke of the common characteristics of lying, stealing/shoplifting, inappropriate behaviors in this population. Thirteen of the fourteen children and teens focused on in this study are currently or have in the past had problems with shoplifting, stealing, inappropriate friends, and inappropriate sexual behaviors. These behaviors apparently happen within the population regardless of the secure stable environment provided by parents/caregivers.

The impulsivity seen in the behaviors of these individuals and the problems with understanding consequences for their actions makes the incidence of shoplifting/stealing easy to understand.

"He repeatedly takes things from the store. We make him take them back and apologize but it doesn't prevent them from happening again."

"He stole batteries once and I went with him to the store and made him apologize and return them."

Prevention of this problem for two parent/caregivers means their children, ages 12 and 17, are still not allowed to go to a store alone.

One caregiver remembers a shoplifting episode at the age of 18. "With his own money I recommended he hire a lawyer. He did. I asked the lawyer to frighten him away from any repeat shoplifting. The lawyer used his mental health record to get him off with 15 hours of community service. The lawyer and I leveled with him about the dangers of criminal behavior when over the age of 18 and also the fact that he was a person of color...and not getting equal justice in the system. We had no more trouble with shoplifting."

Stealing was cited by all but three of the parents as a problem, most often mentioning incidents of stealing at home with family members or friends and the objects most commonly are toys, food, keys or money.

Dealing with inappropriate friends is a problem commonly cited by parents/caregivers. As one parent/caregiver shares: "He always picks the worst kids he can find." Another states his son "was easy prey for some kids that picked on others."

Within the male population of FAS/FAE individuals, inappropriate sexual behavior was mentioned by half of the respondents. Masturbating at a young age and in inappropriate social settings was mentioned by several within this group. A preoccupation with questions of a sexual nature was also mentioned frequently. Perhaps the most disturbing to parents is the four reports within this group regarding inappropriate sexual touching of younger children. Counseling and open discussions are the methods used by all parent/caregivers in dealing with all of these issues. Streissguth et al. (1988), discuss the need for birth control and sex education for FAS individuals. "As adolescents, these patients tend to be sexually curious, yet they often lack understanding of socially appropriate sexual behavior."

"He masturbates in front of people.. and says sexual remarks to our daughter. We tried to get him to masturbate privately, not in front of others. If he masturbated we would make him go to his room for 10 or 15 minutes. We have just repeated this over and over and over. We also stressed not to touch other people's private parts."

School Issues

For many educators FAS/FAE is a barely-mentioned subject in their college curriculum for teacher preparation. For those seeking specialization in behavioral or special education issues, additional information regarding FAS/FAE is included only in some college curricula. The exclusion of the material comes more from the problem of there being very little research available regarding curriculum and classroom issues for individuals with FAS/FAE.

For most teachers in the classroom today, their first in-depth information about FAS comes with the diagnosis of a child in their classroom or school. Their information in these instances comes from parents, the diagnosing agency or professional, growing numbers of professional workshops on the subject, or individual research by the teacher.

There are many excellent teachers dealing with the educational needs of this special population, just as there are teachers whose lack of understanding of the syndrome and its characteristics are failing to meet the educational and behavioral needs of these individuals.

Giunta and Streissguth (1988) in "Patients with fetal alcohol syndrome and their caretakers" mention the need for appropriate educational

FAS and FAE Children in the Classroom

- They often need reteaching; seem to be always "starting from scratch."
- They are very schedule dependent and have difficulty adjusting to unexpected changes in the schedule.
- They cannot seem to follow verbal instructions, even though they do hear them.
- They are often accused of daydreaming, low motivation, and not playing attention.
- They sometimes resist "changing gears" to another kind of activity.
- They tend to complain that they were just getting involved when suddenly they are expected to keep up with something that's moving faster than they are.
- They tend to resist rules and fantasize that things would be fine if there were no pressures from rules or structure.
- They have oversensitivity to stimulus, hypersensitivity to criticism and difficulty following through with tasks to the end. Once interrupted, they cannot remember the task or where they were in the process of doing it.
- They try hard academically and in life skills areas, but the results are quite often disappointing, leading others to repeatedly prompt them to "try harder" or "just put their minds to it."
- They experience fatigue from the regular stimulus level of the classroom and regularly show exhaustion after a typical school day, displaying exaggerated tiredness, emotionality or blunted effect (psychic exhaustion).
- They take up to three times longer to complete schoolwork and homework that would take other children under an hour to complete.
- They may show a hypersensitivity to sensory input.
- They may have some form of sleep disturbance.
- They seem curiously "younger" than peers their age.
- They have impaired ability to gauge cause and effect but can be trained to use deductive logic to improve their problem-solving skills.
- They are poor at generating potential choices in a linear way.
- They are easily frustrated and need frequent encouragement even on tasks that don't seem out of the ordinary for a child the same age (remember to bring home the right school books).

Adapted from: Rathbun, Antonia. (1990, September). "FAS and FAE Children in the classroom" in Growing with FAS: A fetal alcohol syndrome network publication.

placement in special education classes. "A small classroom setting with clear guidelines and a great deal of individual attention to students can help these patients maximize their intellectual capabilities. In a regular classroom setting, these students' short attention spans and distractability may compound their intellectual deficits...Teachers at all levels should have training and information about fetal alcohol syndrome in order to help them recognize and understand the problems facing these

children. Familiarity with FAS can help teachers set realistic performance expectations and tailor their teaching methods to the special needs of students with FAS."

The parents/caregivers in our survey shared the characteristics of successful teachers and best years and less successful teachers and worst years in their child's educational history. The similarity of their descriptions of both types of professionals is telling. Admittedly, the characteristics you see listed here are those all parents wish to see in their children's teachers, but for a student with special needs, these characteristics can determine success or failure for a school year.

Of the fourteen subjects in this survey, two currently attend private or parochial schools; one is out of school; and ten are in public schools, both urban and rural; and one is being home-schooled through the public school system. All of these students are receiving or have received special education services as needed, and all but the oldest have been mainstreamed into age appropriate classes where possible.

"Most successful teacher, best year"

"Most successful" teachers and "best year in school" were often described in the same terms as the structural needs at home. Parents list most often the need for structure with flexibility, consistency in behavioral expectations, an understanding of the student's reactions to change, and a warm accepting environment as the components for success in the classroom.

Successful teachers were described as:

- "Warm and cares about him;"
- "The teacher was the parent of an ADHD child with much insight. She was willing to make adaptations and try new things."
- "... gave him a constant build up."
- "...same teacher he has had for three years. She is consistent, has set rules with set consequences which she follows through with and is willing to work with me to problem solve and communicate."
- "Our first male teacher and he is a good role model as well as providing all the qualities necessary for him to succeed. He is willing to give my son extra time and try different things."
- "She was patient, understanding and encouraging."
- "A male music teacher who is a lovable, gentle, enjoyable and patient man."
- "A special ed teacher who pushed him hard to get his written work in and she realized she had the right to ask him to do what he could do. She was tenacious."
- "Patient, loving, caring and effective."

Good or successful school years seem to be characterized by several things: regular communication between parents and school, flexibility in the classroom and an understanding of the syndrome and the wide range of characteristics.

- "This seems to be his best year is school yet...We have a very good open relationship (with the teacher). We are able to communicate well."
- "Felt teacher and kids accepted him the way he was. He really liked his male teacher."
- "Teachers were understanding, cooperative and willing to communicate often about positive activities also."
- "His teacher responds to him in a very loving positive way. We are able to communicate with his teacher every day he is in school both before and after school."
- "We communicate all the time. We use grade sheets and assignment sheets and he brings them home every day. The teacher calls if there are any problems."
- "We are in regular communication."
- "Sixth grade and eighth grade were the best. Both times the teachers finally got a program that seemed to work for him and them. They understood him better."
- "We set up a weekly reporting system."

"Least successful teachers, school years"

"Least successful teachers" and "least successful school years" were described by these parents in the following terms:

- "Ninth grade - She tore him down so he would not try and he became very withdrawn and belligerent."
- "First grade - first year of regular education class and the teacher was extremely rigid and did not believe in accommodations."
- "Our schools give timed math fact tests that must be passed at each grade. She insisted our son do these even when the OT (occupational therapist) said he didn't have the physical ability to write that many numbers in that length of time."
- "She took a class on exceptional children and now is an 'expert.' She is not real receptive to my input."
- "Second grade - a teacher who was unorganized, unstructured and inconsistent and could never get a handle on his behaviors. My son went from being a follower to a leader in disruptive behaviors."
- "School has been living hell. There hasn't been a bearable year until now. (Home-schooled)"
- "Third grade - because the teacher was unstructured. My son took advantage of this."
- "Teacher was not on to his tricks. He believed my son no matter how many times he lied. Teacher would not report daily to me; trusted my son to make the right choice because of his IQ and age."
- "First grade - teacher gets angry very easily and has trouble coping with students who do not perform the way she expects them to."

All of our parents responded positively about providing as much information as possible regarding their children's diagnosis and behaviors. But the success of the school district and the teacher to deal with the special needs of their children fluctuated from year to year, and school to school. Several of our parents were very pleased with the school's acceptance of the diagnosis and the willingness of the teachers and administration to work toward realistic educational goals for their children. On the other side of the coin are parents struggling with school administrations and teachers to gain some acceptance of their child's diagnosis and educational needs.

- "Some years are better than others. The diagnosis is there in the records but I'm not sure teachers ever look at the record. They seem to focus on the ADHD and LD problems in isolation."
- "I have provided piles of information to teachers and principals to make them knowledgeable. They have welcomed and appreciated the information."
- "Too many school systems are unwilling to go to any extra trouble to help a child succeed in the regular classroom."
- "They wanted to put him in an old category. They didn't want to start a new one. I made them aware, they knew very little and what they did know was wrong information."
- "His teacher is very aware of his diagnosis. We have talked about FAE and she has seen him at church and in various situations. She has seen his tantrums and how we handle them."
- "The first special ed teacher was very interested and cooperative. She left the school two years ago. The present teacher is arrogant. There is little interest or concern because our daughter is the only one who has been diagnosed as having FAS."

When asked to describe what they as parents see as their children's educational needs and the ability of the school district to meet these needs, again the same descriptive phrases were used: "patience, structure, consistency, encouragement, self-esteem." Parents are asking for educational professionals with patience, who can create a calm, consistent, structured, learning environment. Teachers willing "to adapt their classrooms," "to provide more time for these children to complete their school work," "to provide more encouragement," "to build self-esteem," and "to emphasize practical application of academics to daily living areas." As one parent said, my daughter needs "a special education teacher who realizes that FAS/FAE children are unique, with strengths and weaknesses that vary with each individual case."

Giunta, Streissguth and LaDue in Lincoln, August, 1991, spoke of the need for appropriate vocational and daily living skills training. "...all of these patients need to know basic life skills: money management, safety skills, interpersonal relating

and so forth. These kinds of tasks will enrich their adult lives, allowing them a degree of independence." The addition of a life-skills component to special education curricula for FAS patients is recommended.

"Young people with FAS could benefit greatly from vocational training during the high school years...The high school years should be used to teach these patients skills that they are capable of learning and that will be useful to them in adulthood, namely, life skills and vocational training."

For families of children with FAS/FAE life is a series of on-going challenges. Caregivers/parents of this special population continually bring love, patience, creativity and a sense of humor to the life-long problems they face. Likewise there are many educational professionals who have dealt very successfully with students of this population. Their expertise is needed and should be passed along so other educational professionals faced with an FAS/FAE diagnosis can draw on this knowledge.

Realistic expectations on the part of parents/caregivers, educational and social service professionals are an important aspect of success for individuals with FAS/FAE (LaDue, 1991). Without realistic expectations caregivers and professionals will be easily frustrated, and overcome by feelings of guilt and failure in dealing with the behavioral and psycho-social aspects of FAS/FAE.

Our participating parents/caregivers spoke openly of the need for respite, of the needs of their other children for respite and quality time with their parents. Though acceptance within the extended family was not a problem in most cases, a lack of understanding by extended family of the behavioral and educational difficulties was mentioned by some participants. Support groups, respite programs, educational opportunities for parents and other family members are community services needed for this population.

For individuals with FAS/FAE and their caregivers, there is much work to be done. Appropriate school programs and classroom management are needed, along with appropriate daily living skill and vocational training. Educational and human service professionals need on-going training regarding the characteristics and needs of this special population. Prevention of alcohol-related birth defects through education and public awareness of the risks involved with the consumption of alcoholic beverages in pregnancy is also needed.

A list of professional articles and resources is included with this article to provide the reader with additional information regarding FAS/FAE, including specific educational and behavioral information.

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Appendix

The following 44 questions comprise the survey instrument used to gather behavioral information from participating caretakers of individuals with FAS/FAE:

Name of respondent_____
Address_____ City_____State_____Zip Code_____
Child's name_____ Relationship_____
Current age_____ Age at diagnosis_____
Diagnosis_____ Diagnosed by_____
Current height and weight of child_____
Current living arrangements_____
Please share with us the circumstances of your child's diagnosis:
Current grade in school_____
Last measured IQ_____ What fluctuations in IQ scores has your child experienced?

BEHAVIOR

1. Please describe your child's behavior problems.

2. How are his/her behaviors different from your other children?

3. How many other children are in your family?
   How does your FAS/FAE child get along with the other children in the family?

4. Is your FAS/FAE child hyperactive? If yes, has medication been tried to control it?
   How effective was the medication?

5. Depending upon the age of your child, how has the hyperactivity changed from infancy, early childhood, primary school, elementary school, junior high and high school?

6. Please describe the structure you provide for your child at home?

7. How has the structure changed with his/her age?

8. What "house rules" does your child have the most difficulty with?

9. Please describe how your child deals with consequences? Has his/her understanding of consequences changed with age?
   Please share an incident to describe his/her problems with consequences.

10. Please describe your child's sleeping patterns.
    Are they the same now as when he/she was younger? If no, please describe the differences.
    What effective means have you found to deal with unusual sleeping patterns?

11. Please describe your child's eating patterns. How are they different from when he/she was younger?

12. How does your child get along with other children? What age group of children is he/she most comfortable with?

13. What are your child's favorite activities or hobbies?

14. What types of behavior management have you tried with your child?

15. Have you received professional help in designing a behavior management program for your child? If yes, was it useful?
    What positive reinforcements have been successful with your child? How have these changed over the years?

16. Please describe the responsibilities or "chores" your child handles at home?

17. How does your child respond to verbal cautions?

18. How does your child respond to strangers?

19. How does your child respond to changes in his/her environment?

20. Please share with us your child's involvement in any of the following behaviors. What have you tried and what has been effective in dealing with any of these problems? Shoplifting; Stealing; Inappropriate friends, gangs; Alcohol and drugs; Inappropriate or questionable sexual behavior; Others.

SCHOOL

21. Type of school attended (public, private, parochial, city, rural).

22. What type of classroom is your child in?

23. What special education services does your child receive?

24. What special education services has your child received in the past?

25. What was your child's best year in school and why?

26. What was your child's worst year in school and why?

27. Please describe your child's most successful teacher.

28. Please describe the least successful teacher your child has had.

29. What type of relationship do you have with your child's teacher this year?

30. How often are you in communication with the school and/or the teacher?

31. How does the teacher respond to your child's behavior?

32. How effective is the teacher and school in dealing with your child's behavior?

33. Is your child's teacher aware of his/her diagnosis and if so, how would you describe the information level of the teacher regarding FAS/FAE?

34. Please share with us any positive or negative experiences you have encountered with school systems and educational professionals.

35. Please describe what you see as your child's educational needs.

36. How well is your school district meeting these needs?

FAMILY/COMMUNITY

37. Please describe the degree of acceptance your child has received within your family and extended family?

38. How well do other family members accept his/her behaviors, problems, hyperactivity?

39. What special needs does your family have?

40. How supportive is your extended family to these special needs?

41. What community groups or agencies have been most helpful to you and your family? Why?

42. As a caregiver, what special needs do you have?

43. Are these needs being met? If so, by whom?

44. Do your other children have any special needs regarding your child with FAS/FAE? What are these needs? How are they being met?